



The Research Connection

The Psychosocial & Nursing Advisory Board to
the New Jersey Commission on Cancer Research

Editor: Kathleen Walsh Scura, Ed.D., RN

Number 1

The Joint Psychosocial & Nursing Advisory Group to the NJCCR was appointed to advise the Commission of special research needs pertaining to nursing, psychology, sociology, and related disciplines for the purpose of addressing gaps in vital areas of cancer research and cancer care in New Jersey.

2006 Psychosocial & Nursing Advisory Group Members

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DEFINING AND ASSESSING QUALITY OF LIFE

by
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What is it? Trying to define and measure the elusive concept of “quality of life” has been the source of endless, ongoing and consistently perplexing debate. The NJCCR Psychosocial/Nursing Advisory group elected to define it as *a patient’s sense of well being which includes the perception of physical, psychological and spiritual functioning.*

The World Health Organization defines health not simply as the absence of disease, but rather a complex, multidimensional system in which an individual’s well-being and ability to function are major factors. As an emerging and significant theme in health care, positive outcomes are now measured not only as quantity, but *quality* of life. Although definitions of

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quality abound, it is generally agreed that *patients* should determine what they need to feel “well,” which symptoms are most destructive to that well-being, and their satisfaction with the level of quality that they experience.

As in myriad other issues, New Jersey has accepted the role of pioneer in the consideration of quality of life. Under the aegis of the NJCCR, national and regional experts in the quality of life consideration gathered for a Roundtable Discussion more than two years ago, and provided a blueprint for advancing discussion and movement in quality of life assessment. The discussion was approached from three distinct perspectives:

- The individual practitioner-patient relationship;
- The responsibilities of the institutions and agencies providing care; and
- The role of the community and healthcare organizations.

Despite the considerable ongoing national and local debate about the precise definition and “best practices,” roundtable participants voiced strong support for taking immediate action in initiating or strengthening QOL assessment in clinical, institutional and community settings. While the concept of the patient’s right to quality of life principles has been integrated into many research protocols and clinical trials, this idea has not been as readily adopted into the delivery of clinical care. National funding and accrediting agencies are currently considering some mandates relative to QOL and may soon impose such requirements.

Barriers

The roundtable identified some of the challenges to a more universal and rigorous adoption of quality of life standards, including:

- A lack of understanding about the concept of quality of life among both professionals and the public;
- The dearth of appropriate and validated assessment tools targeted to the cancer population at significant milestones in the disease progression, as well as training for the effective administration of those instruments that are available;
- The dual and intense pressures of high patient volume and limited staff availability that serve to inhibit the consideration of quality of life

assessment and intervention in most clinical settings;

- A perception that QOL assessment requires extensive skills and resources not available in most settings;
- An appreciation that conducting a quality of life assessment carries the ethical imperative to respond with interventions that are often poorly defined, elusive, and/or costly.
- The need to assist patients in accepting their “right” to information and partnership in QOL decisions in a culturally competent and sensitive environment.

As an outgrowth of the Roundtable, the NJCCR undertook to create a Task Force on Quality of Life and to initiate two major surveys of attitudes about Quality of Life; one for physicians and the other directed at nurses.

Benefits

A commitment to quality of life assessment and intervention can present a significant challenge to healthcare professionals and patient advocates. Nonetheless, progress is being made in the adoption of principles of quality of life in clinical care. Measuring QOL has proven benefits: enhanced patient-provider communication; improved treatment satisfaction and quality of care; and the ability to more effectively document the clinical course (Cella, 2003). QOL assessment is an important tool in evaluating the effectiveness of an intervention in clinical trials, and is essential in Phase III and IV trials. QOL consideration can identify gaps and unmet needs in the delivery of care, and play a role in the development of new programs, policies and resource allocation. Other benefit include:

- Assisting in patient decision making, directing efforts to screen for and reduce symptoms considered destructive of quality survival, characterizing the burden both the illness and the treatment imposes, evaluating alternative treatment options, and helping to predict outcomes (Cella, 2003); and
- Measuring the impact of physical functional losses (mobility, ability to work and provide economic support) and psychological losses (helplessness, anxiety, fatalism, depression).

In addition, despite the difficulties outlined above, a number of tools designed to measure the patient’s perception of quality of life are being investigated.

Methodologies include face to face interviews, patient completed questionnaires, and computer assisted formats. Efforts are continuing to identify the ideal venue; waiting room, home, telephone discussion, among others. Effective tools must adapt to pressing time and language demands, be short enough to encourage participation but demonstrate a comprehensive approach to ensure benefit and provide a means of immediate feedback to the practitioner.

Moving Forward

The consensus of the Roundtable on Quality of Life was that ***the first and most important step is the need for each individual, practitioner and organization in the state to become an advocate for incorporating QOL measurement and assessment into the delivery of care.***

A number of steps will be necessary to fully adopt the best practices and standards of quality of life assessment universally into clinical care. Everyone involved in healthcare delivery in New Jersey can become an active participant in this process. Some of the steps include:

- Becoming involved and recruiting others with interest, knowledge and skills in QOL in cancer care settings to participate;
- Supporting comprehensive surveys of current QOL assessment and measurement practices that include practitioners, institutions and agency efforts, policies and resources allocated for their accomplishment;
- Identifying accepted QOL assessment tools and promoting their dissemination to the healthcare community;
- Establishing and participating in educational programs to enhance understanding of quality of life concepts and ameliorating the barriers, obstacles and concerns;
- Promoting institutional, personal and community agency policies that are responsive to cultural, ethnic, geographical and literacy differences, as well as disparate settings, disease states and centers of care;
- Advancing advocacy for the use of QOL as a significant factor in treatment planning,
- Encouraging statewide and national organizations such as the NJ Medical Society, Oncology Nurses Society, Oncology Social Workers, American Cancer Society, Cancer Care, etc. to become

involved in the effort to educate and advocate for inclusion of QOL assessment in healthcare delivery.

The action steps and principles identified can be adopted and promoted by individuals, organizations and institutions. Learning about the role and impact of quality of life assessment and intervention is the responsibility of all healthcare professionals as well as community advocates, consumers and patients.

References for this article are available by contacting the NJCCR at 609-631-4747 or (njccr@doh.state.nj.us).

Challenges of Measuring Quality of Life

by

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A recent (30 Nov 2005) on-line search of Pubmed for “quality of life” references yielded a staggering 74,743 articles. Of those, 18,531 were cancer related quality of life (QOL) articles. Many of the articles address treatment related side effects and QOL measurements obtained during clinical research studies. Still others identified cognitive impairment and psychosocial issues related to chronic illness, such as cancer.

There are many reasons why QOL is difficult to measure. This article will explore some of the reasons why measuring QOL is important and remains an ongoing challenge for healthcare professionals.

Defining QOL

QOL is a complex multidimensional concept which spans the physical, emotional, social and spiritual dimensions of an individual. Influenced by such variables as culture, age, and lifestyle, QOL is highly individualistic and for that reason experts agree that QOL must be defined by the patient (Cella and Cherin, 1988; Velikova et al., 2004).

QOL is dynamic in all individuals, but for the cancer patient QOL is influenced by such events as treatment related symptoms, physical well-being, psychological well-being, or pain (Osoba, 2000). Therefore, attempts to utilize QOL measurement for clinical purposes are best represented by multiple

measurements taken at different timepoints throughout a patient's care.

Some dimensions of QOL include:

- Physical well-being (activity level, symptoms, health status, cognitive function),
- Social well-being (ability to socialize, social support, family relationships, role function),
- Psychological or emotional state (distress or well-being, anxiety/worry, body image),
- Spiritual well-being,
- Level of work or vocational performance,
- Ability to meet economic needs or maintain economic stability,
- Satisfaction with healthcare and with the provider-patient relationship,
- Sexuality and/or fertility,
- Future outlook,
- Existential factors (security, respect, autonomy).

Why Measure QOL

QOL has been an area of interest for decades, and many different methods have been used to measure QOL. Measurements of concepts contributing to QOL have been ongoing for years. Such contributory concepts include pain, adjustment to illness, physical well-being, and performance status. Through the years research of the above mentioned concepts have been conducted; however, none of concepts alone are surrogates for overall QOL.

One might ask, with all of the research done to date, is there a need to continue to explore QOL? This seems a fair enough question, and one that warrants discussion.

For many cancer survivors, faced with the diagnosis of a potentially life threatening disease, maintaining activities and QOL remains a goal (Repetto et al, 2001). Many cancer survivors will express a desire to maintain a desired level of QOL, rather than longer survival with a diminished QOL. This is a generalization; therefore, each individual must be approached to assess his or her goals. QOL and survival remain a key discussion points for goal setting with cancer patients. On an individual level, discussing QOL facilitates open communication, provides information

about the patient's perceived current health status, and promotes discussion about future healthcare decisions (Velikova, et al, 1999). Mossman and Slevin (1999) consider QOL a key component of good cancer care.

A wealth of information about a patient or groups can be obtained by measuring QOL. By studying QOL Gotay and Muraoka (1998) have identified positive coping strategies used by some cancer patients, as well as groups of patients at risk for problems, or those who will benefit from intervention. Moreover, the importance of symptom control, supportive care measures and effective medical interventions can be obtained through QOL measures (Gotay & Muraoka, 1998; Osoba, 2000; Velikova, et al., 1999).

Instruments to Measure QOL

There are many comprehensive QOL instruments; in fact, over 200 QOL instruments exist. There are specific tools for different types of cancer (e.g. FACT P for prostate cancer) which were developed by experts to incorporate specific symptoms related to the underlying cancer or treatment options.

Some comprehensive and widely used instruments include, but are not limited to:

Psychosocial Adjustment to Illness Scale (PAIS, Derogatis, 1986)

QOL-CS (Quality of Life – Cancer Survivors (Gotay & Muraoka, 1998)

Rotterdam Symptom Checklist (symptoms) (RSCL) (deHaes, J. C., vanKnippenberg, F.C., Neijt, J. P. (1990).

Short Form 36 (SF-36) (Ware and Sherbourne, 1992)

European Organisation for the Research and Treatment of Cancer QLQ-C30 (EORTC QLQ-C30) – domains plus global (“excellent candidate for broader use in clinical setting” Velikova et al., 1999)

Functional Assessment of Cancer Therapy –General (FACT-G) (Cella et al., 1993) (“excellent candidate for broader use in a clinical setting” Velikova et al., 1999)

Functional Assessment of Chronic Illness Therapy (FACIT) (see Webster, Cella, Yost, 2003)

Functional Living Index – Cancer (FLIC) (Marrow, Lindke, & Black, 1992).

Long-term Quality of Life (LTQL) questionnaire
(Wyatt et al, 1996; Wyatt & Friedmann, 1996)

Deciding on what instrument to use in a facility, or for research, is as complicated a decision. This challenge is one that is best addressed by a multi-disciplinary group. Some considerations for evaluating instruments include:

- What type of facility or research is involved?
- What resources are available to administer and review, or record and analyze the questionnaire(s)?
- Will patients with a single type of cancer be evaluated, or patients with different types of cancer?
- Will patients from diverse cultures be evaluated?
- Will the spouse or significant other be included in the measurement? Some instruments such as the PAIS (Derogatis & Derogatis,) have been used to measure spousal adjustment to illness (Hoskins, et al).
- How will the results be translated into care, referral or resources for the patient and/or family?
- Can clinical trials be used to evaluate the effectiveness of the measurements?

Let's not forget that cancer patients also have other concomitant diseases that impact QOL. QOL includes people with heart disease, RA, lung disease, etc. Many people with cancer are living longer and develop other chronic illnesses that impair their QOL.

This article has outlined some of the challenges of measuring QOL. Additional challenges for healthcare professionals exist. Continued collaboration between QOL experts and community healthcare providers is needed. Instrument refinement, measurement procedures, analysis of research findings, evaluation and implementation of best practices at the community level remain of paramount importance. By meeting these challenges, the value of QOL measurement and interventions will be available within the community arena, thus promoting QOL for each individual patient.

References for this article are available by contacting the NJCCR at 609-631-4747 or (njccr@doh.state.nj.us).

Tools for Measuring Quality of Life

by

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Quality of life (QOL) is increasingly recognized as an important dimension of overall health status. Research suggests that routine use of QOL instruments as part of clinical practice has the potential to improve the quality of care that patients receive as well as their health status. The importance of measuring QOL is further validated with the introduction of U.S. Senate bill S.2965 "The Quality for Individuals with Cancer Act." A central focus of this legislation is on the development of a core set of quality cancer care measures.

The multidimensionality, complexity, and individuality of how QOL is perceived by each patient warrant the use of evidenced-based QOL assessment tools. Currently there are a number of instruments available that have been shown to have adequate reliability and validity. Many of these tools are able to distinguish patient outcomes that reflect quality of life. Gaining knowledge of which health care providers are measuring QOL and how they are assessing QOL must be pursued with the same rigor as the study and development of effective QOL measurements.

In 2002 the Nursing and Psychosocial Advisory Group of the NJCCR and Rutgers University conducted a survey that focused on New Jersey medical oncologist's use of QOL assessment in their practices, their knowledge of specific QOL instruments, and any barriers they face to using these tools. Results indicated inconsistent practices throughout the state. In 2004, nurse researchers at Seton Hall University College of Nursing and the NJCCR initiated a similar study that assessed oncology nurses' use of standardized QOL tools.

Although 88.6% of the oncologists responded that they ask their patients about overall well-being or QOL at every visit, only 12.4% use standardized tools. Whereas for the nurses 64% responded that they ask their patients about overall well-being at every visit, and 23% responded that they used standardized tools. Physical symptoms were assessed significantly more often than psychosocial symptoms ($p < .001$) by both the oncologists and the nurses. Responding to questions

that rated the usefulness of various standardized tools to measure QOL oncologist and nurses rated standardized QOL instruments as moderately useful [oncologist mean = 3.0, (SD=.3); nurse mean =3.7 (SD=4) on a scale of 1-5]. The greatest barrier that both oncologists and nurses faced using standardized tools for assessing QOL was identifying tools that are valid and reliable (oncologist-74%, nurses-64%).

This work is relevant to the treatment of cancer patients because understanding the use of formal QOL tools and knowledge of barriers to the application of

QOL tools can provide a basis for the educational needs of providers. The comprehension of these provider barriers to QOL tools is important when considering the development or improvement of QOL measurements.

In addition, a better understanding will foster effective approaches and interventions for patient care. Awareness of patient's perceptions about their QOL facilitates better communication and care and illuminates the capacity to appreciate the uniqueness of individual experience.

Health Related Quality of Life Assessment Tools for Cancer Patients

Name of Questionnaire	Brief Pain Assessment	Brief Fatigue Inventory	Distress Thermometer	FACT-G	FACT-G	LCSS Scale	Medical Outcomes Study Short Form-36	Northwestern Health Profile	Pain Scales	Pain Thermometer	Rotterdam Symptom Checklist	Sickness Impact Profile
Developer	Charles S. Chiodini, 1989	The University of Texas, M.D. Anderson	James H. Holland, MD, PhD	European Organization for Research and Treatment of Cancer, 1993	David Cella, 1993	Prinzmetz and Ravn, 1974	Rand Corporation and John T. Ware, 1980	Lucia Sher, 1981	Calibration	James Holland, MD, PhD	ECN de Haas, TCI van Rossum, J.H. Prager, J.P. Hoog	Richard Rogers, Revised in 1981
Description	Measures the severity of cancer pain and its impact on the patient's functioning.	To assess the severity of fatigue and the impact of fatigue on daily function in cancer patients.	A rapid screening tool to measure distress in cancer patients.	Measures various aspects of QOL of cancer patients participating in randomized clinical trials.	Used in oncology research and to assess symptoms and QOL issues that are relevant to various forms of cancer.	Widely used in QOL research in oncology.	Physical functioning, role limitations due to physical and emotional problems, pain, social functioning, overall health, energy level, health perceptions.	Designed to give a brief indication of personal, physical, social and emotional health problems.	There are a variety of versions.	A rapid screening tool to measure pain in cancer patients.	Cancer-specific tool to measure psychological and physical distress in cancer patients participating in clinical research.	Evaluates the impact of disease on physical and emotional functioning. Patient's required to choose as they are on that day.
Number of Items	20	11	1	30	27	25	36	38	1	1	30 + 8 on ACEs	24 statements in 12 categories
Categories	Intensity of pain, impact of pain, selected words to which best describes the pain and indication to the extent and duration of pain relief from analgesia.	Patient disability as a result of their fatigue and duration and severity of the fatigue.	Rates distress.	Function, symptoms, overall judgment of health status and physical and emotional well-being.	Overall QOL, physical, social, emotional, and functional well-being.	Symptoms, aspects of functioning, and overall QOL.	Used in conjunction with disease specific measures as an outcome measure in clinical practice and research.	Physical mobility, pain, social roles, emotional, functional, reactions, energy, sleep.	Used to indicate the level of pain felt by a patient.	Rates pain.	Physical and psychological symptoms, and ACEs.	Dimensions include physical, psychological and independence (ie, eating, working, components).
Administration	Self or interviewer	Self or interviewer	Interviewer	Self or interviewer	Self	Self	Self or interviewer	Self	Self	Interviewer	Self	Self or interviewer
Time to Complete	10-15 minutes	5 minutes	Under a minute	11 - 12 minutes	5 minutes	5-10 minutes	5-10 minutes, 11 for the short form	5-10 minutes	Under a minute	Under a minute	8 minutes	5-10 minutes (self), 10-15 minutes (interviewer)
Scoring of Items	0-10 point scale to record the intensity of the pain and the impact of the pain.	0-10 point scale to record the level of fatigue.	A picture of a thermometer numbered 0-10 is shown to a patient. The patient is then asked, "How would you rate your pain today on a scale of 0 to 10?" There is also a set of "Yes" or "No" questions.	Variety of "Yes" and "No" questions and 4-point scale and Likert scale questions.	Likert rating scale from 0-4.	Grading of a 100-millimeter bar with descriptors at each end. Patients mark their status along the line.	"Yes" and "No" questions. Symptom and quality scale questions.	"Yes" and "No" questions.	7 picture faces vary from a smile to a frown. In each picture, a number is shown.	A picture of a thermometer numbered 0-10 is shown to a patient. The patient is then asked, "How would you rate your pain today on a scale of 0 to 10?"	4-point scale.	Respondents check only the statements that describe them (positively).

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Dr. Wendy Budin and Nancy Chiodini of Seton Hall University, College of Nursing, created this Quality of Life Assessment Tool Poster to be used as a quick reference guide in a healthcare setting.

Copies can be obtained free of charge by calling the NJCCR at 609-631-4747.

GETTING TO KNOW YOU

A Series of Interviews with Members of the Psychosocial/Nursing Research Community in New Jersey

This issue highlighting
LARISSA LABAY, Psy.D

By
Denyse L. Adler, MA

Choosing an academic path and a career focus, finding funding, pursuing special interests and

integrating family life all presented special challenges and opportunities to Dr. Larissa Labay. Dr. Labay, a child psychologist with the Tomorrows Children's Institute (TCI) and Cure and Beyond, the Childhood Cancer Survivorship Program at Hackensack University Hospital, faced all of these options and decisions in creating her career path.

Motivated by the disheartening lack of psychosocial support available for her father or the family when he died of cancer, she decided at 16 that she would pursue psychology and try to assure that other families had the support and services that she lacked. She decided on pediatrics and faced the broad and often overwhelming decisions about where and

what to study, developing a specific focus and finding funding to help support her studies.

Her research focus grew during both undergraduate and graduate studies. As a research assistant at Wesleyan University, she was drawn to clinical research issues and the opportunity for direct interaction with participants. The decision to pursue research also flowed from the MA program at New York University in Community Psychology. The focus of the program, developing and implementing primary prevention interventions for high risk populations, was research oriented. The research priority was also a factor in selecting a doctoral program, and Dr. Labay identified the opportunity to integrate research with clinical services by selecting the Psy.D program at Rutgers. In addition, working with funded clinical scientists also provided welcome student stipends. Joining a research project as a student was a practical choice to help fund school fees, but turned into a real passion for Dr. Labay.

Integrating the demands of family and career are very familiar challenges. Dr. Labay chose to return to Hackensack following the recent birth of her baby, initially to a somewhat reduced schedule; although she has quickly learned that “reduced” is more in name than reality. She currently divides her time between TCI and the survivorship program. Her work is divided about 75% clinical and 25% research.

The main focus of her current research is the transition year following active treatment as the youngsters move into a survivorship mode. The study, “Childhood Cancer: A Prospective Examination of the Transition from Active Treatment to Cancer Survivorship,” is funded by the Tomorrows Children’s Institute. The protocol includes interviews of parents and children prior to the termination of treatment and then after three, six, and twelve months. Dr. Labay reports that the anxiety level of parents in this period is very high; despite assumptions that going back to a “normal life” would be welcome, parents express fear of relapse, loss of the supportive atmosphere of the institution, coping with school and peer reactions, and how to manage medical emergencies. While the patients don’t face the same anxieties, they are concerned about having missed both school advancement and social interactions and may feel the lack of peer relationships. They don’t want to be handled with “kid gloves.” The ongoing research

project is an attempt to identify the specific fears expressed by both groups.

Dr. Labay served as principal investigator of studies on Empathy and Psychological Adjustment in Siblings of Children with Cancer, and is currently co-investigator of a project examining Attention Deficit Hyperactivity Disorder in Survivors of Childhood Acute Lymphocytic Leukemia and is site Principal Investigator in a study of Cognitive Behavioral Intervention for Bone Marrow Transplant Survivors. These are collaborative projects with other researchers at TCI.

While Dr. Labay acknowledges that she is in an enviable and in many ways supportive environment to pursue research, conducting investigation of healthcare issues can be daunting. In her facility research is highly prized, she has access to excellent mentors, the program is nationally recognized and sought as a collaborative partner, and the TCI is highly motivated to support innovative and meaningful research issues. Nonetheless, even in this environment, moving a protocol through an IRB unaccustomed to psychosocial outcomes, obtaining consent, finding funding and recruiting both professionals and research subjects can present significant challenges. Making the time to publish and to participate in national professional organizations is also an imperative.

Dr. Labay recognizes how intimidating the idea of launching into a research project or investigation might be, especially for clinicians with little or no research experience. However, responding to that intellectual curiosity that compels an attempt to understand some phenomenon, can be very fulfilling and exciting, and worth some extra effort. She does warn that often the responsibilities attached to research may require many home or “off work” hours.

She has some very practical and compelling advice for clinicians and students who are hoping to expand their opportunities in research, perhaps even while maintaining a demanding clinical role.

- *Find a mentor.* Whether in an academic or clinical environment, it is important to seek out someone who can provide meaningful leadership and direction and be supportive of your ambitions. This might be someone inside or *outside* of your own institution.
- *Be prepared to become involved in your mentors research priorities first, before you can move into*

your own. Often a principal investigator has funded research in which you can participate. This can provide experience, track record, and possibly some funding as you learn about research. You may be able to piggyback your own interests on some other research programs.

- *Seek out peers to share your research interests.* It can be difficult to find like-minded colleagues, but it is worth the effort to take some of the intimidating aspects out of the idea of research.
- *Ask your supervisor and institution for support of your research interests.* It is important to have this support and approval. Many institutions and/or national professional organizations have some funds available for small pilot projects. This can be a good starting point for your project.
- *Be prepared to put in “extra” time to prepare even a rudimentary outline of your interests, read the literature or contact colleagues.*
- *Identify the gaps in your own skills and education and seek out education and information.* Even the most experienced researchers do not have skills or training in all components of research; courses, literature or online resources can help to fill those gaps.
- *Find colleagues with the skills and training you lack to collaborate.* Each professional in the project brings special knowledge and hopefully some passion to the effort.
- *Reach out to medical professionals to advocate for the integration of psychosocial research and to help them understand the role and relevance of psychosocial factors in oncology.* While

psychosocial components of care will always be secondary in a treatment environment, they can be demonstrated to have a major and significant impact on treatment compliance, quality of life and survivorship.

- *Try to join professional organizations that can provide peers, mentors, support and training to help enhance your research interests.* These may be regional or national organizations but many offer funding, training and education.
- *Look to your academic ties; schools you attended and faculty who may be involved in research.* These connections can often direct you to collaborative opportunities or meaningful training.
- *Look for funding for your projects.* Initial efforts are generally small pilot projects and may not need extensive funding. They will help you to learn the system and develop important relationships. Your hospital or organization may be able to help. For bigger projects, a track record is necessary, so seek out other like-minded researchers with whom to collaborate. Get some training in grant writing.

Dr. Labay has found her “niche” and the beginnings of a gratifying career in pediatric clinical and research arenas. She encourages other health professionals to follow their interests, instincts and passion and to begin with small steps toward their goals.



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